



California Sudden Infant Death Syndrome Advisory Council

Minutes of the August 13, 2013, Meeting

Members of the Council

Thomas G. Keens, M.D.,
Chair, Physician member.

Lorie Gehrke, *Vice Chair,*
SIDS Parent.

Kitty Roche, R.N., P.H.N.,
B.S.N., M.S.W. *Secretary,*
Public Health Nurse

Kathleen Beichley, *SIDS*
Parent

Dawn Dailey, R.N., P.H.N.,
Ph.D., *Public Health*
Nurse.

Steven Durfor, *Police/Fire*
First Responder.

James K. Ribe, M.D.,
Medical Examiner.

Dennis H. Watt, *Coroner.*

Vacant, *SIDS Parent.*

Penny F. Stastny, R.N.,
B.S.N., P.H.N.,
President, Southern Calif.
Regional SIDS Council.

Aline Armstrong, P.H.N.,
President, Northern Calif.
Regional SIDS Council.

Council Chairperson:

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California SIDS Advisory Council
Los Angeles, California, October 29, 2012

- **Members Present:** Thomas G. Keens, M.D., *Chair*; Lorie Gehrke, *Vice Chair*; Luz Arboleda-Babcock, P.H.N., as alternate for Kitty Roche; Aline Armstrong, P.H.N.; Kathleen Beichley; Dawn Dailey, RN, PHN, PhD; Steve Durfor; Penny F. Stastny, R.N., B.S.N.; and Dennis Watt, Coroner.
- **Members Absent:** Kitty Roche, *Secretary*, and James K. Ribe, M.D.
- **State and California SIDS Program:** Guey-Shiang Tsay, RN, MSN.
- **Guests:** Shanna Anseth, R.N.; Claudia Benton, R.N., P.H.N.; Gwen Edelstein, RN, PNP, MPA; Abby Freed; Devra Hutchinson; Rachel Strickland; and Steve Wirtz..
- **Alternate Council Members:** In accordance with the Standing Rules of the California SIDS Advisory Council, *Luz Arboleda-Babcock, P.H.N.*, was designated as the alternate for Council Member *Kitty Roche, R.N., B.S.N., P.H.N., M.S.W.*, who could not attend today's meeting.

- The meeting was held by telephone conference call. A quorum of greater than 2/3 of Council members was present. The meeting was called to order at 1:35 P.M., on August 13, 2013.

- **Introductions.**

Council members, state staff, and guests introduced themselves.

- **California SIDS Advisory Council: Membership.**

- *Yolanda DeMello* is leaving the *California SIDS Advisory Council*. She was one of three legislated SIDS parent members. The Council thanks *Yolanda* for her service to the Council and to the California SIDS Community since joining the Council in 2011.



Yolanda DeMello

- The *California SIDS Advisory Council* is now seeking a SIDS parent member to fill the current vacancy. Interested SIDS parents should submit a letter of intent and a resume or curriculum vitae, which highlights his or her SIDS activities. California law mandates that three of the nine Council members must be SIDS parents. The role of the SIDS parent is specifically to bring the needs of SIDS parents to the attention of the Council, and thereby to the California Department of Public Health. The SIDS parent must reside in California. Please send the above to both:

- *Thomas G. Keens, M.D.*, Chair, California SIDS Advisory Council, at tkeens@gmail.com
- *Guey-Shiang Tsay, R.N., M.S.N.*, Nurse Consultant III, California Department of Public Health, at Guey-Shiang.Tsay@cdph.ca.gov

The deadline for receipt of applications is September 15, 2013. Although applications may be reviewed by Council members, the final decision who to appoint as a Council member is made by the Director of the California Department of Public Health.

- Appended to these Minutes are the “Standing Rules for the California SIDS Advisory Council”. Of note, meetings can not be officially held without a quorum of at least 2/3 of members (nine) present. However, if a member knows in advance that he or she will miss a meeting, he or she may designate an alternate to attend in place of the member. This alternate, will count toward the quorum. The Chair noted that membership on the Council is a high honor. However, it also carries responsibilities. Therefore, Council members are urged to attend all meetings they can. When members know, in advance, that they may not be attending, please work with the Council Chair to designate an alternate for you during this meeting.

- **State Report.**

Guey-Shiang Tsay presented a report of the California SIDS activities of the Maternal, Child, and Adolescent Health (MCAH) Division of the California Department of Public Health.

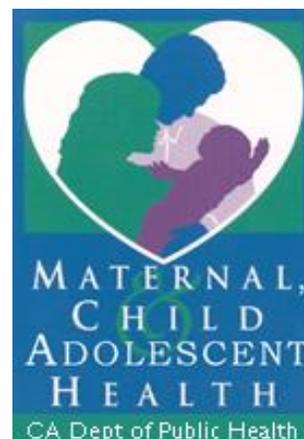
During June, we worked with the California State University Long Beach Foundation to make the California SIDS Program transition as smooth as we could. During this transition period,

there were many important issues that needed to be completed. Thanks to *Gwen Edelstein* and *Cheryl McBride* for their coordination efforts. I would also like to thank the MCAH staff and SIDS Council for the support I received. This was a great collaboration among my supervisors, Contract Manager and her supervisor, *Carrie Florez*, and myself. We hope to minimize the impact of disruption in services from this transition period, and we want to assure you that MCAH is committed to continuing the California SIDS Program.

Some important updates:

- **Proposed SIDS Contractor:** We developed an interagency agreement with the Regents of the University of California, San Francisco (UCSF), School of Nursing, and we have submitted the SIDS contract through MCAH Management and to our internal Contract Management Unit (CMU). MCAH is working closely with CMU and UCSF during the contract process, and we will keep you informed of our progress. It is hoped that UCSF will take on the California SIDS Program contract before December, 2013.
- **Website:** Currently, there is a plan within CDPH to move all off-site websites back to the Department. Our CDPH IT staff is working with us to transition the components of the original California SIDS Program website to the Department. There are still some technical difficulties to work out (broken links, removing outdated resources, etc). We will continue to work with ITSD to resolve these issues, and our next step is to work with an internal design team to restore the website and maintain it as a Departmental site and resource to the community. We will keep you posted on this issue also. The old California SIDS Program site is still available but it is not being kept up-to-date. However, it remains a rich resource for information and materials.
- **SIDS Awareness Month in October.** We are planning to promote the SIDS risk reduction messages at the State level, and we are in the process of requesting a letter from the Director of the California Department of Public Health supporting October as SIDS Awareness Month.
- *Carrie Florez* is currently working on the 2011 SIDS data and statistics.
- **Reporting/Documenting Suspected SIDS Cases.** Documentation required by both the coroner's office and the local health department for all suspected SIDS cases continues. Please continue to send the Reports to *Carrie Florez*. She will review and process the reports submitted by coroners and local health jurisdictions. If you have any questions, please contact *Carrie* at Carrie.Florez@cdph.ca.gov.
- **State SIDS Conference and Boatwright Award.**

The 2013 California SIDS Conference, to be coordinated and hosted by the Northern California Regional SIDS Council, has been postponed until 2014, when we presumably will have a *California SIDS Program* to help with the logistics. It was agreed that the Northern California



Regional SIDS Council should plan and hold the 2014 California SIDS Conference, to be held in October, as they have already done quite a bit of planning for this conference. Following this, California SIDS Conferences will continue to alternate between the Northern and Southern California Regional SIDS Councils. Therefore, the 2015 California SIDS Council will be planned and coordinated by the Southern California Regional SIDS Council, etc.

The Daniel E. Boatwright Award “for extraordinary public service on behalf of Californians touched by sudden infant death syndrome” is traditionally chosen by the Regional Council planning the annual SIDS conference that year, and the award is traditionally presented, usually as a surprise, to the recipient, at the annual SIDS conference. As there is no annual conference this year (2013), the question arises whether or not to award the Boatwright Award in a different venue. The consensus was that this award is so important, that it deserves the visibility of being presented during the annual conference. Therefore, the Boatwright Award will not be made this year (2013), but it will be resumed at the 2014 California SIDS Conference, with the recipient selected by the Northern California Regional SIDS Council.



**California State
Senator Daniel E.
Boatwright**

- **SIDS Risk Reduction Education.**

- **Los Angeles County Infant Safe Sleep Campaign.**

Jessica Spearman Was not able to participate in the Council meeting, but she sent this report of the impressive progress made by this program for inclusion in these Minutes.

The ICAN/ICAN Associates LA County Infant Safe Sleeping Campaign: Safe Sleep for Baby has spent the spring of 2013 preparing for and launching the Safe Sleep for Baby Campaign. The campaign was launched on May 8, 2013, at California Hospital. Safe Sleep for Baby Campaign collateral materials were debuted including the 30 second Safe Sleep for Baby PSAs in English and Spanish, 60 second Radio Spots in English and Spanish and outdoor advertisements in English and Spanish. Campaign representatives also unveiled a new bilingual website, www.safesleepforbaby.com and a new bilingual pamphlet. In addition to debuting the campaign media materials, a half hour press conference was held with speakers



**Jessica B.
Spearman**

including ICAN Executive Director, Deanne Tilton Durfee, Director of Public Health, Jonathan Fielding, LA County Coroner investigator, Denise Bertone, and Eviana Magee, a young mother who lost her baby due to infant unsafe sleeping. Press interviews following the press conference also included Infant Safe Sleeping Task Force member, Dr. Carol Berkowitz, and Francisco Oaxaca of First 5 LA.

Approximately 33 news outlets attended the Safe Sleep for Baby campaign launch with approximately 15 news cameras present. Through the assistance of the IW group, the Asian media was heavily represented. This allowed campaign staff to ensure that the message of infant

safe sleeping would reach this important demographic even though they are not heavily represented in infant unsafe sleeping deaths.

Safe Sleep for Baby radio ads can currently be heard on local radio stations including Power 106, KJLH and La Raza and billboards can be seen in communities throughout the County. Currently, ICAN and Social Marketing Firm Rogers Finn Partners are working with Metro to place ads on the interior and exterior of Metro transit vehicles.

During the summer of 2013, ICAN/ICAN/ICAN Associates has continued to partner with stakeholder agencies for the Safe Sleep for Baby Campaign Partnerships. Agencies are asked to partner with the campaign and use campaign materials to educate staff about infant safe sleeping practices and urge staff to share infant safe sleeping information and tips with the families they work with. To date, ICAN/ICAN Associates in Partnership with First 5 LA have partnered with the 12 Los Angeles Child Abuse Councils and with the ICAN Policy Committee members. Additional outreach has been conducted to all of the Los Angeles County birth hospitals and e-blasts have been sent to the entire ICAN and Safe Sleep for Baby e-mail databases.

Since the campaign launch, partners and potential partners have reached out to ICAN/ICAN Associates after hearing radio ads, seeing billboards, visiting the new Safe Sleep for Baby website and watching news coverage about the campaign. This additional form of raising awareness has resulted in several new partnerships with local and county wide community based organizations.

ICAN/ Associates would like to request all California SIDS Advisory Council Members that are interested in Partnering with /ICAN/ICAN Associates, please e-mail us at info@safesleepforbaby.com. Additionally, Council Members are urged to e-mail or call ICAN (626) 455-4585 for material requests. ICAN/ICAN Associates can accommodate both large and small scale material requests.

ICAN/ICAN Associates will spend the rest of the summer, fall, and winter months developing Safe Sleep for Baby Partnerships (both new partnerships and existing partnerships.)

All Safe Sleep for Baby training and media materials, including the Safe Sleep for Baby Training Tool Kit, e-learning course, Safe Sleep for baby PSAs and Safe Sleep for Baby radio spots, pamphlets and more can be found online at www.safesleepforbaby.com.



- **SIDS, Undetermined, or SUID Diagnoses.**

Penny Stastny commented that a recent parent, whose baby was diagnosed as “Undetermined”, had no problem accepting that diagnosis when it was explained that SIDS, Undetermined, SUDI, and SUID all mean the same thing in the eyes of the Coroners and Medical Examiners

who make the diagnoses (the the death is unexpected on the one hand, and unexplained on the other). She reiterated that the parents of all of these infants should all receive the same education and grief support from Public Health Nurses that was previously given to SIDS families.

There was some discussion about whether or not there was an official document indicating that families of babies dying with all of these diagnoses are entitled to public health nurse visits and other education and grief support services by County Public Health Nurses. The California SIDS Advisory Council formally recommended to the California Department of Public Health that this should be the case on August 14, 2012. A copy of our formal recommendation is appended to these Minutes. Subsequently, the MCAH Title V Director sent a letter endorsing this recommendation to all California Coroners, Medical Examiners, County Health Departments, County SIDS Coordinators, and County MCAH Directors on December 17, 2012. A copy of this letter is appended to these Minutes. The California SIDS Advisory Council was pleased that the California Department of Public Health acted so promptly on our recommendation. It would appear that this document provides the authority needed by County Health Departments to provide these services to families of infants dying with the diagnoses of SIDS, Undetermined, SUDI, SUID, etc.

- **Council's Role in SIDS Parent Support.**

There was no discussion on this issue.

- **Public Health Nurse Issues.**

Dawn Dailey and *Kitty Roche*, the Public Health Nurse representatives on the California SIDS Advisory Council, are continuing to support county SIDS Programs by contacting newly appointed SIDS Coordinators. *Guey-Shiang Tsay* notifies *Dawn Dailey* (Northern California) and *Kitty Roche* (Southern California) when a new county SIDS coordinator is appointed. This is a crucial activity to ensure that new coordinators are welcomed and informed of the statewide SIDS resources and council structure.

Since public health nurses are now being asked to make home visits on families of babies dying with SIDS, Undetermined, SUDI, and SUID diagnoses, *Claudia Benton* (*Ventura County SIDS Coordinator*) asked if there were materials which were more generic on grief, which could be distributed to families who did not have a SIDS diagnosis. Although many existing materials specifically reference SIDS, increasingly, materials are available which refer to SIDS and other infant deaths. Many of these materials are already referenced on the *California SIDS Program* website. Even when a new contractor is in place for the California SIDS Program, it is unlikely that there will be sufficient budget to develop such materials. Thus, public health nurses are encouraged to use existing resources. The *Southern and Northern California Regional SIDS Councils* were identified as venues where nurses could share resources they found valuable.

- **First Responder/Coroner Investigator Issues.**

Dennis Watt stated that the California State Coroners' Association is considering holding a second "SIDS Summit" to continue to address issues of the diagnosis of infants who die suddenly and unexpectedly in California. There are no definitive plans as to date or format of this conference.

- **Southern California Regional SIDS Council.**

Penny F. Stastny, R.N., B.S.N., P.H.N., President of the Southern California SIDS Council, reported on the activities of the *Southern California Regional SIDS Council*.



**Southern California Regional SIDS Council.
May 9, 2013, Meeting**

- Our most recent *Southern California Regional SIDS Council* meeting was held on May 9, 2013, in Huntington Beach. We had 12 members present including five of our county SIDS Coordinators from Los Angeles, San Diego, Orange, Ventura, and Long Beach; two SIDS parents; Dr. Jim Ribe representing LA Coroner's office; Dr. Keens from CHLA and USC; and Gwen Edelstein.
- We started our meeting by presenting *Gwen Edelstein* with flowers and our first *SIDS Lifetime Achievement Award* from the Southern California Regional SIDS Council. *Penny Stastny* did share her personal history with *Gwen*. She and *Gwen* graduated together in the same nursing class from California State University Long Beach in 1971. *Penny* wanted all of our State SIDS Council members and others on this call to know that *Gwen's* time, energy and efforts can never be totally replaced. Her *SIDS Lifetime Achievement Award* read as follows:

Let It Be Known to All People, that
Gwen Edelstein, RN, PHN, PNP, MPA
has enriched the lives of thousands of people through her steadfast service and extraordinary achievements improving SIDS services, education, and research in California. In recognition thereof, the Southern California Regional SIDS Council awards her its highest honor:

SIDS Lifetime Achievement Award

Penny went on to say, "*Gwen*, the Southern California Regional SIDS Council doesn't even know how to begin to describe all that you have done for each and every one of us. Words will never adequately express the deepest and greatest gratitude that we all have for you. You have made such a huge, extraordinary difference in the way our SIDS Program has run for the past 23 years."

- We had a great and informative council meeting, and I will not go into all of the reports given. However, *Dr. James K. Ribe, Los Angeles County Coroner Office* reported:
 - On the morning of May 9, 2013, we had all local television stations at Los Angeles County Coroner Office to unveil the Safe Infant Sleep Campaign and to tour the mobile

autopsy van. Jessica Spearman's focus groups made it clear that the one safe government agency in the public's eye is the Coroner Office. This Office is viewed as being on the side of the poor people: it won't throw you in jail, it won't take kids away, it won't take welfare benefits ... they are not the enemy. The Department of Children and Family Services, (DCFS) is being much more aggressive in their handling of SIDS families, and it is something to bring to our attention.

- When infant deaths are occurring in Los Angeles County, DCFS is taking other children out of home and launching an investigation into the home and the parents. In the past this only happened when something was suspicious. Presently because these deaths are seen as preventable, many of these parents are viewed as doing something wrong. This is causing parents to have to prove they are worthy – takes months and needs lawyers and a formal procedure. Dr. Ribe stated that DCFS is under pressure from the Los Angeles County Board of Supervisors. We discussed how the Los Angeles County PHN can be a support to parents before and/or help them with the understanding of the role of DCFS. The PHN's role is definitely shifting with an emphasis of now having to explain the role of DCFS as well as police, coroners, etc.



Southern California Regional Sudden Infant Death Syndrome Council

Let It Be Known to All People, that

Gwen Edelstein, R.N., P.H.N., P.N.P., M.P.A.

Has enriched the lives of thousands of people through her steadfast service and extraordinary achievements improving SIDS services, education, and research in California. In recognition thereof, the Southern California Regional SIDS Council awards her its highest honor:

SIDS Lifetime Achievement Award.

Awarded this ninth day in the month of May in the year Two-Thousand Thirteen, in Huntington Beach, California.

Penny F. Stashy, R.N., B.S.J.
President, Southern California Regional SIDS Council

Thomas G. Keens, M.D.
Chair, California SIDS Advisory Council

- *Doctor Keens* asked those on the *California SIDS Advisory Council* meeting if there were any other counties using DCFS in this manner. There do not appear to be.
- The *Southern California Regional SIDS Council* is committed to continuing to meet in person to air and attempt to resolve problems in the South, even in the absence of a California SIDS Program. We will plan that the 2015 Annual California SIDS Conference will be coordinated by the *Southern California Regional SIDS Council*.

- **Northern California Regional SIDS Council.**

Aline Armstrong, P.H.N., President of the Northern California Regional SIDS Council, reported on activities of the *Northern California Regional SIDS Council*.

- *Northern California Regional SIDS Council* meeting was held on July 19, 2013, at 9:30 am to 11:00 am via telephone conference call. The next meeting will be on September 20, 2013 face to face at 9:30 am to 12:30pm.
- The council had 8 members on the calls. The highlight of the meeting was Guey's report on the potential SIDS Contractor: State MCAH is in the process of pursuing an interagency agreement with UCSF. UCSF staff is working with their administration to obtain approval to proceed with the contract. State MCAH will still need to go through MCAH Management and the internal Contract Management Unit. MCAH is working closely with UCSF in the contracting process and will keep us informed.



Northern California Regional SIDS Council,
February 1, 2013.

- *Guey-Shiang Tsay* informed that the Annual California SIDS Program Conference has been postponed, and shared the plans for the SIDS Website being moved to the State MCAH Website. All PHNs reports and coroners reports should be sent to *Carrie Florez*.
- All SIDS Coordinators are continuing to work hard and submitted their SIDS reports.

- **Council Meetings in 2013.**

The remaining *California SIDS Advisory Council* meeting for 2013 is:

- Meeting by telephone conference call, Tuesday, October 1, 2013, 1:30-3:30 P.M.

By law, meetings of legislatively mandated advisory councils are open to the public. Therefore, anyone interested in participating in *California SIDS Advisory Council* meetings is welcome and encouraged to attend.

- **Adjournment.**

The meeting was adjourned at 2:45 P.M.

Respectfully submitted,

Thomas G. Keens, M.D.

Chair, California SIDS Advisory Council



Standing Rules

California Sudden Infant Death Syndrome Advisory Council

Maternal, Child and Adolescent Health

1. Purpose

In 1989, Senate Bill 1070 required the Department of Health Services (CDHS) to establish the Sudden Infant Death Syndrome (SIDS) Advisory Council. The description of the SIDS Advisory Council and its duties are contained in Health and Safety Code Section 123725.

2. Functions

- a. Provide guidance to the State Department of Health Services (DHS), Maternal, Child and Adolescent Health (MCAH) in the development of training, educational and research programs regarding SIDS;
- b. Provide ongoing guidance to the Governor and the Legislature regarding the need for SIDS programs for specific targeted groups of persons; and
- c. Convene a statewide conference annually, in conjunction with DHS or a person with whom DHS contracts, to provide SIDS education. The purpose of the conference is to examine the progress in discovering the cause of SIDS, explore the progress of newly established programs and services related to SIDS, identify future needs for legislation and program development regarding SIDS, and make recommendations of the needs of programs regarding SIDS.

3. Structure

- a. Agenda items will be presented by staff, or invited experts and discussed as a group.
- b. Following discussion of each agenda item, the Council will consider resolutions containing recommendations to the Governor, the Legislature and /or MCAH staff.
- c. At the close of each meeting, the Council will recommend topics for future agenda items, and confirm the date and time of the next meeting.
- d. A quorum is defined as a minimum of two-thirds of the members being present at a Council meeting.
- e. Minutes of Council meetings recorded and approved by a vote of the Council members constitute the complete record of Council discussions and recommendations.

4. Meeting Location and Frequency of Meetings

- a. Council meetings with on-site attendance will be convened once a year in conjunction with the annual SIDS conference. Additional on-site meetings, in Sacramento, will be scheduled at the discretion of MCAH.
- b. Teleconferences will be scheduled periodically.

5. Categories of Participation

There will be three categories of Council participants:

- a. **Members** - Section 123725 of the Health and Safety Code provides that the Advisory Council shall consist of nine members who shall be chosen by the DHS Director in consultation with regional SIDS Parent Advisory Councils. Council Members shall serve without compensation, but shall be reimbursed for necessary and travel expenses incurred in the performance of the duties of the Advisory Council. Members may vote.
- b. **Liaisons** – Representatives from non-MCAH government offices and or programs invited to provide technical expertise as needed on specific items of consideration for the Council. Liaisons may not vote.
- c. **Attendees** – Interested public, staff from MCAH and MCAH contractors and their staff, as needed, for specific meeting agenda items. Attendees may not vote.

6. Member's Absence- Designee

A Member who anticipates his or her absence from a Council meeting may request substitution by a designee who meets those requirements in Health and Safety Code section 123725 for the position occupied by the Member requesting substitution. Such requests must be made to the Chair of the Council and approved in advance of the meeting. Designees shall be eligible for reimbursement of necessary and travel expenses, and may vote.

7. Officers of the SIDS Advisory Council

- a. A Council Chair shall be appointed annually by the MCAH Programs and Policy Chief to preside over the Council meetings.
- b. The Vice Chair shall be elected annually by the voting Council members and shall serve as Chair in the absence of the Council Chair.

8. Conflict of Interest

- a. Although Members are not covered by the Political Reform Act, Members shall agree to voluntary verbal disclosure of potential conflicts of interest to relevant discussions. The Member can either voluntarily recuse herself or himself from voting on the issue or can request that the Committee as a whole determine whether a potential conflict exists and if recusal from voting should be applied.
- b. If recusal from vote either is self-applied or applied by the Council as a whole, participation in any discussion regarding the matter is permitted.

9. Accommodation of Visitors and Guests

- a. Council Meetings are open to the public.
 - b. MCAH staff and Council members may invite guests.
 - c. The Council's Members may adjourn to Executive Session without recorded minutes.
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**Official Recommendation of the *California SIDS Advisory Council*
to the *California Department of Public Health*: August 14, 2012.**

**Diagnosing the Cause of Death for
Infants Dying Suddenly and Unexpectedly**

Diagnosing the cause of death for infants who die suddenly and unexpectedly has become increasingly difficult. In California, and in much of the rest of the world, there is a disparity in the way the causes of death for these infants are determined. In some jurisdictions, such infants may have a cause of death listed as "SIDS", in some "Undetermined", in still others "Sudden Unexplained Infant Death". This has resulted in confusion in the California SIDS community. Are coroners trying to suggest that babies in these diagnostic groups are fundamentally different? Should parents of a baby who died from "SIDS" be more reassured than a parent whose baby was listed as "undetermined"? Should parents be treated differently, or offered different resources, depending on the diagnosis used?

The *California Sudden Infant Death Syndrome Advisory Council* has spent considerable time and effort investigating these issues, and it has come to consensus for the State of California. The *Council* has determined the following:

- Coroners and medical examiners in California face considerable challenges in determining the cause and manner of death for infants who died suddenly and unexpectedly. These deaths were not witnessed, so Coroners must attempt to reconstruct the possible cause of death by investigating circumstantial evidence from the death scene and autopsy. Most deaths are associated with one or more potential risks or potentially unsafe sleeping environments, which complicate interpretation of the cause of death. While coroners are doing their best to accurately determine the cause of death, certainty is rarely possible. Thus, some disparity in how these babies are diagnosed is inevitable. It is not likely, or perhaps even desirable, that complete consensus is achieved by all California coroners to diagnose these babies the same.
- Coroners may have differing philosophies and/or practices which will influence them to make certain diagnoses more commonly than others. However, in the absence of a clear-cut finding indicating a specific cause of death, it is clear that the terms "SIDS", "undetermined", "sudden unexpected death of infancy", and "sudden unexpected infant death", are being used interchangeably. To coroners, these all mean that the death was sudden and unexpected, and that it was unexplained (that is, we do not know the cause). Therefore, the California SIDS community, public health departments, and everyone interacting with these families should view these diagnoses as being equivalent and meaning the same thing.
- Coroners in keeping with the SIDS legislative mandates (California Government Code 27491.41) should refer all sudden unexpected infant deaths to their local health jurisdiction's SIDS Program Coordinator within 24-hours of completing the autopsy. This trained Public Health Nurse/Social Worker in accordance with California Health and Safety Code 123740 should make contact with the family within three working days to provide counseling, support and bereavement assistance. This should include families where the baby is diagnosed as dying

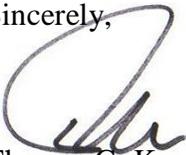
from "SIDS", as well as families with diagnoses such as "undetermined", "sudden unexpected death in infancy", "sudden unexpected infant death", etc.

- Contact by the local health jurisdiction should be a face-to-face visit, a group visit or a telephone call. However, a home visit is recommended whenever possible. Those who experience a sudden unexpected infant death, regardless of the diagnosed cause, should not be treated differently. A home visit is the preferred supportive intervention as this provides an opportunity for the bereaved to express their feelings, gain an in depth understanding of the circumstances of their infant's death, and ask questions. For many, the home visit is the foundation of their support.

The Council is aware that for some parents, receiving a diagnosis of "undetermined" has been interpreted as somehow tainting the death as suspicious, compared to a diagnosis of "SIDS". It is clear from discussions with coroners and medical examiners that this is not their intent. Rather, in the minds of California coroners and medical examiners, these diagnoses are essentially interchangeable, and they imply only that the death was sudden and unexpected on the one hand, and unexplained on the other. It is now the responsibility of public health departments, coroners, and SIDS experts not to perpetuate the above view, but to emphasize that these deaths are similar in the eyes of those making the diagnoses, and that parents of all of these babies are entitled to the same support, education, empathy, and respect.

The *California Sudden Infant Death Syndrome Advisory Council* officially and unanimously approved this recommendation at its meeting on August 14, 2012.

Sincerely,



Thomas G. Keens, M.D.
Chair, California SIDS Advisory Council.



RON CHAPMAN, MD, MPH
Director & State Health Officer

State of California—Health and Human Services Agency
California Department of Public Health



EDMUND G. BROWN JR.
Governor

DATE: DECEMBER 17, 2012

TO: COUNTY CORONERS, SHERIFF CORONERS AND MEDICAL EXAMINERS
SUDDEN INFANT DEATH SYNDROME (SIDS) COORDINATORS
MATERNAL, CHILD AND ADOLESCENT HEALTH (MCAH) DIRECTORS

SUBJECT: SUDDEN, UNEXPECTED INFANT DEATH TIMELY REFERRALS AND PROVIDING
GRIEF/BEREAVEMENT SUPPORT SERVICE TO PARENTS/CAREGIVERS WHO
EXPERIENCE A SUDDEN, UNEXPECTED INFANT DEATH

This letter is in reference to the current MCAH Scope of Work (SOW). Within the SOW, each Local Health Jurisdiction (LHJ) MCAH program is required to contact all parents/caregivers who experience a presumed SIDS death to provide grief and bereavement support services. California HSC §123740, requires local health officers to contact persons having custody and control of the infant to provide information and support services. It is very critical that the LHJ receives the timely referral from the coroner/medical examiner's office in order for SIDS Coordinators/Public Health Professionals to provide grief/bereavement support services to all parents/caregivers who experience a presumed SIDS death.

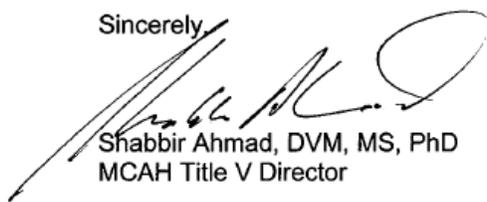
With the introduction of the International Classifications of Disease, 10th Revision (ICD-10) in 1999, causes of death listed on the death certificate that will be classified to SIDS (R95) in California include Crib Death, SDII (sudden death in infancy), SIDS, SUD (sudden unexplained death), SUID (sudden unexplained infant death), SUDI (sudden unexplained death, infant) and SID (sudden infant death). It is very important for the coroner/medical examiner's office to voluntarily refer all sudden and unexpected infant deaths to the local MCAH program, including deaths with an "undetermined" diagnosis. The California SIDS Advisory Council recommends that any person interacting with families who may receive one of these diagnoses be provided the same grief/bereavement support and SIDS education as a family who receives a SIDS diagnosis.

We are very grateful for the continued support of coroners/medical examiners referrals of sudden, unexpected infant deaths even with the continued suspension of the state mandates due to state budget constraints. We also appreciate local MCAH SIDS Coordinators/Public Health Professionals for providing grief/bereavement support services to all parents/caregivers who experience a presumed SIDS death that are referred to their offices. The collaboration between the coroner/medical examiner office and local MCAH Program is essential when an infant dies suddenly and unexpectedly. It is difficult for the parents of the infant to deal with such a tragic loss and the availability of support services to help them work through their loss could be critical and beneficial.

CORONERS-AND MEDICAL EXAMINERS
SIDS COORDINATORS
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We look forward to continuing to work with all of you together. If you have questions, please feel free to contact Guey-Shiang Tsay, Nurse Consultant for the SIDS Program, at Guey-Shiang.Tsay@CDPH.ca.gov, or Carrie Florez, Research Scientist for Epidemiology Evaluation and Data Operations, at Carrie.Florez@cdph.ca.gov.

Sincerely,



Shabbir Ahmad, DVM, MS, PhD
MCAH Title V Director

California SIDS Advisory Council



Kathleen Beichley



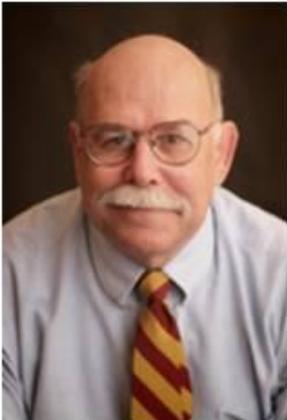
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Steve Durfor



Lorie Gehrke



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